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SUPPORTIVE CARE

The impact of parental cancer on children and the family: a review of the literature

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Children;
Psychosocial
functioning;
Parent–child
relationship;
Family functioning

Summary Objective. Children of cancer patients may go through a distressing time. The aim of this review was to survey present knowledge on the impact of parental cancer on children and the family.

Design. Studies published between January 1980 and March 2004 addressing emotional, social, behavioural, cognitive and physical functioning of children of a parent diagnosed with cancer, as well as the association with child, parental and familial variables were reviewed.

Results. Fifty-two studies were found. Emotional problems in school-aged children (≤ 11 years) were reported in several qualitative studies, but in only one quantitative study. Quantitative and qualitative studies reported anxiety and depression in adolescents (≥ 12 years), in particular in adolescent daughters of ill mothers. Quantitative studies generally showed no behavioural and social problems in school-aged children and adolescents. One quantitative study found physical complaints in school-aged children. However, qualitative studies revealed behavioural problems in school-aged children and also described restrictions in cognitive and physical functioning in children of all ages. The most consistent variables related to child functioning appeared to be parental psychological functioning, marital satisfaction and family communication. Intervention studies directed to the needs of children and their families reported positive effects.

Conclusion. While quantitative studies reported especially disturbed emotional functioning, qualitative studies reported problems in all domains of child functioning. Well-designed studies are needed to gain more insight into the psychosocial functioning of children of cancer patients in order to develop tailored care.

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Introduction

The impact of cancer on patient's psychosocial functioning has received considerable attention in the literature during the past two decades. A

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growing number of studies have addressed the psychosocial consequences for the spouse. However, limited attention has been paid to the effects on children when a parent is diagnosed with cancer. Confrontation with parental cancer can be very threatening for children and may result in the development of psychosocial problems, such as anxiety, confusion, sadness, anger, and feelings of uncertainty with respect to the outcome of the illness. They may face many changes in daily family routines due to repeated hospital admissions, hospital visits and care of the parent when at home.

This study reviews the current state of knowledge on psychosocial consequences for children who have a parent diagnosed with cancer, and on variables that influence these children's functioning. The findings will be organized around the following questions. Firstly, what is the impact of parental cancer on children, in terms of their emotional, social, behavioural, cognitive and physical functioning? Secondly, is there evidence that child, parental or familial variables are associated with the functioning of children who have a parent diagnosed with cancer? Thirdly, are there evidence-based interventions described which may help parents and children cope with this major life event?

Methods

A comprehensive search of the literature published after 1980 was conducted, using MEDLINE, EMBASE, PsycINFO, CINAHL, and CancerLit databases. The keywords used in this search were: 'neoplasm', 'parental cancer', 'mothers and cancer', 'fathers and cancer', 'parent-child-relations', 'child functioning', 'quality of life', 'children and anxiety or depression', 'family functioning', and 'cancer and offspring'. This search was supplemented with manual searches of the reference lists of extracted articles. The initial search yielded a total of 90 studies. Studies were excluded if they were dissertation abstracts, were not in English, reported on the consequences for adult children of a parent with cancer, focussed on related topics (e.g. parenting), or described the bereavement of children of parents who had died of cancer. Of studies that dealt with pre-death as well as post-death adaptation of children, only pre-death information was used.^{1,2} The remaining 52 studies addressed the psychosocial functioning of children aged 0–20 years of parents diagnosed with cancer, and comprised quantitative, qualitative and intervention

studies. Those studies were reviewed independently by the first two authors. Because the methodological quality of studies included may vary, the quality of the quantitative studies was assessed using the guidelines of the Cochrane Library. Studies were considered as methodologically 'stronger' or 'poorer' on the basis of: design, representativeness of the sample, reliability of measurements, and use of control or norm groups.³ The methodological quality of the qualitative studies was evaluated using procedures described by Lincoln and Guba.^{4,5} They suggested four criteria for establishing the trustworthiness of qualitative data: credibility, dependability, confirmability and transferability.

To assess the methodological quality of the studies a standardized form was used for data extraction. In case of disagreement consensus was achieved by discussion among the authors.

Because quantitative and qualitative research approaches are methodologically different, the results of studies will be reported separately. Results reported in the quantitative studies reviewed are considered to be significant only when a level of $p \leq 0.05$ was reached.

Results

Study characteristics

A total of 52 studies met the inclusion criteria. Sample size, informants and illness-related information in the quantitative studies ($n = 14$) and in the qualitative studies ($n = 18$) are summarized in Tables 1 and 2, respectively. Mixed-method studies ($n = 13$) are summarized in Table 3. Intervention studies ($n = 7$) were described in the text only.

The aim of the studies differed: 31 studies reported on the psychosocial functioning of children,^{1,2,6–34} eight studies focused on family functioning or parent-child relationships,^{35–42} four on family communication,^{43–46} one on the adolescents' perceptions of the role of school support,⁴⁷ and one on care-provision by children.⁴⁸ Seven papers described intervention programs for families that were designed to help children cope with their parent's cancer.^{49–55}

In almost half of the studies (46%) only mothers with breast cancer were included. In the remaining studies an overrepresentation of mothers with breast cancer was found.

The majority of studies used a cross-sectional design with the exception of five studies^{6–8,33,37} that used a longitudinal design.

Table 1 Quantitative studies

Study	Respondents	1. Diagnosis; 2. Stage; 3. Time since diagnosis
1. Armsden and Lewis (1994) ⁹	48 children (19♀, 29♂) aged 6–12 years; 13 ill mothers; 11 nurse observers	1. Breast; 2. Not terminal; 3. Range 6–96 mo
2. Barnes et al. (2002) ⁴⁵	32 mothers of 56 children aged 5–18 years (20♀, 35♂)	1. Breast; 2. I or II; 3. Range 4–6 mo
3. Birenbaum et al. (1999) ¹⁴	115 youngsters (31 latency-aged children, 84 adolescents)	1. Breast (65%), genital; urinary; reproductive (18%), haematological (17%), others (9%)
	66 ill parents (52♀, 14♂) and 54 partners	2. I: 47%, II: 24%, III: 8%, IV: 12%, missing: 9%; 3. Range 3–64 mo
4. Harris and Zakowski (2003) ³²	27 adolescents (18♀, 9♂) aged 12–19 years from 22 families; 23 controls	1. Breast (55%), gynaecological (18%), other (27%); 2. N.i.; 3. 1–5 years
5. Heiney et al. (1997) ¹⁵	33 children (16♀, 17♂) aged 5–12 years (<i>n</i> = 21) and 13–17 (<i>n</i> = 12)	1. Cancer (N.i.); 2. N.i.; 3. N.i.
	22 ill parents (19♀, 3♂)	
6. Hoke (2001) ²⁰	35 children (21♀, 14♂) of 28 mothers with breast cancer	1. Breast cancer or benign biopsies; 2. I: 48%, II: 44%, III: 7%; 3. Mean 6.7 mo
	34 children (17♀, 17♂) of 24 mothers with benign breast biopsies	
	Children both groups aged 8–16 years, mean age 11.6 years	
7. Lewis et al. (1989) ³⁸	19 well fathers of 19 latency-aged children	1. Breast; 2. Non-metastatic; 3. Median 35.3 mo
8. Lewis and Hammond (1992) ³⁷	111 ill mothers with one or more latency-aged or adolescent children (number N.i.)	1. Breast; 2. 0–II: 93.7%; III, IV: 6.7%; 3. Median 27.4 mo
9. Lewis et al. (1993) ³⁶	40 ill mothers and 40 partners with latency-aged children	1. Breast; 2. 0–II: 88.6%; III, IV: 11.4%; 3. Median 13 mo
10. Lewis and Hammond (1996) ³⁵	70 adolescents (56% ♀, 44% ♂); 70 ill mothers; 70 well partners	1. Breast; 2. 0–II: 97.6%; IIIA: 2.4%; 3. Mean 23.6 mo
11. Siegel et al. (1990) ³⁹	27 well partners (15♀, 12♂); Community sample: 44 parents (25♀, 19♂);	1. Cancer (N.i.); 2. Terminal disease; 3. N.i.
	Reports on children aged 7–16 years	
12. Siegel et al. (1992) ¹²	62 children (aged 7–16) from 42 families	1. Cancer (N.i.); 2. Terminal disease; 3. N.i.
	Community sample: 556 students (aged 7–16 years) from 434 families	
13. Tercyak et al. (2001) ¹⁶	20 children (14♀, 6♂, mean age 14.9) of 15 mothers	1. BRCA 1–2 mutation carriers: 80% symptomatic; 2. N.i.; 3. N.i.
14. Welch et al. (1996) ⁸	34 latency-aged children (50% ♀); 55 adolescents (60% ♀)	1. Breast (37%); gynaecological (20%); others (43%); 2. I: 29%; II: 36%; III: 22%; IV: 13%;
	54 ill parents (80% ♀) and 36 spouses (33% ♀)	3. T1 Mean 9.7 weeks; T2: 4 mo post-diagnosis

N.i., no information; 0, I, II, III, IIIA, IV: stage of disease as described by authors (stage 0, in situ).

Twenty studies used normative data for comparison purposes,^{2,7–9,14–23,35–38,41,42} while a community sample of comparable subjects served as the control group in four studies.^{12,13,32,39} Normative data comprised the scores of a large

group of randomly selected respondents on a standardized questionnaire. The manual of a questionnaire provided those norm scores.

Data on child functioning and related variables were obtained from different informants: eighteen studies

Table 2 Qualitative studies

Study	Respondents	1. Diagnosis; 2. Stage; 3. Time since diagnosis
1. Barnes et al. (2000) ⁴³	32 mothers of 56 children aged 5–18 years (20♀, 35♂)	1. Breast; 2. I or II; 3. Range 4–6 mo
2. Berman et al. (1988) ¹	10 adolescents aged 11–17 years; 7 surviving parents (4♀, 3♂)	1. Cancer (N.i.); 2. Terminal disease; 3. N.i.
3. Chalmers et al. (2000) ⁴⁷	31 adolescents (22♀, 9♂) aged 12–20 years from 27 families	1. Breast; 2. I: 32%, II: 6%, remission: 39%, unknown: 23%; 3. N.i.
4. Christ et al. (1993) ²⁵	87 latency-aged children (aged 7–11 years) from 76 two-parent families with a terminally ill parent	1. Cancer (N.i.); 2. Terminal disease; 3. N.i.
5. Christ et al. (1994) ²⁶	120 adolescents (aged 11–17 years) from 86 two-parent families with a terminally ill parent	1. Cancer (N.i.); 2. Terminal disease; 3. N.i.
6. Fitch et al. (1999) ⁴⁰	47 ill mothers of 1–4 children aged 4–18 years	1. Breast 36%, haematological 19%, gynaecologic 12%, others: 33%; 2. N.i.; 3. N.i.
7. Gates and Lackey (1998) ⁴⁸	11 adolescents (8♀, 3♂) aged 10–19 years (mean: 14) caring for adults from 7 families	1. Multiple myeloma, lung, breast, pancreas; 2. N.i.; 3. N.i.
8. Helseth and Ulfsaet (2003) ³³	10 families: patients (7♀, 3♂), spouses (3♀, 5♂) and children (4♀, 7♂) aged 7–12 years	1. Cancer; 2. Not terminal; 3. N.i.
9. Hilton and Elfert (1996) ⁶	3 families with pre-schoolers and latency-aged children 5 families of latency-aged children and younger adolescents 4 families with older adolescents	1. Breast; 2. Early stage; 3. T1 at diagnosis
10. Hilton and Gustavson (2002) ³¹	11 children (7♀, 4♂), aged 7–21, from six families	1. Breast; 2. N.i.; 3. ≤ 2 years
11. Hymovich (1993) ³⁰	10 families: patients (3♀, 7♂), and spouses (1♀, 2♂) of 26 children aged 9 weeks–20 years	1. Solid tumour 70%; leukaemia 30%; 2. N.i.; 3. Range 4 weeks–7 yrs
12. Issel et al. (1990) ¹⁰	35 children aged 6–12 and 46 adolescents aged 13–20 years from 50 families (1–3 children per family)	1. Breast; 2. Not terminal; 3. Mean one year
13. Kristjanson et al. (2004) ⁴⁶	31 adolescents aged 12–18 years	1. Breast; 2. I–II: 29%; III–IV: 7%; Recurrence: 13%; Remission: 39; Advanced or terminal: 13%; 3. N.i.
14. Rosenfeld et al. (1983) ²⁷	8 adolescent daughters aged 12–20 years from 7 families	1. Breast; 2. N.i.; 3. Range 2–3 years
15. Shands et al. (2000) ⁴⁴	19 mothers of 30 children aged 7–12 years	1. Breast; 2. 0: 6%; I: 33%; II: 39%; III: 17%; IV: 6%; 3. Mean 12.6 mo, range 3–32 mo
16. Spira and Kenemore (2000) ²⁸	adolescent daughters aged 12–19 years (number N.i.); referred to social worker	1. Breast; 2. N.i., 2 recurrences; 3. N.i.
17. Zahlis and Lewis (1998) ¹¹	26 ill mothers of 36 children aged 8–12 years (19♀, 17♂)	1. Breast; 2. 0–II; 3. Mean 39 mo, range 23–56 mo
18. Zahlis (2001) ²⁹	16 adolescents (8♀, 8♂), aged 11–18 years) from 11 families	1. Breast; 2. 0–II; 3. Mean 56.6 mo, range 43–64 mo

N.i., no information; 0, I, II, III, IV: stage of disease as described by authors (stage 0, in situ).

gathered information from the child only,^{2,10,12,13,16,17,19,20,25–29,31,32,46–48} nine from one of the parents,^{11,21,37–40,43–45} twelve studies from the child and

parent(s),^{1,7,8,14,15,18,22–24,33–35} four studies from both parents,^{6,30,36,42} and two studies from the child and/or parent(s) and another closely related person.^{9,41}

Table 3 Mixed-method studies

Study	Respondent	1. Diagnosis; 2. Stage; 3. Time since diagnosis
1. Compas et al. (1994) ¹⁸	50 adolescents (58% ♀), 26 latency-aged children (42% ♀) 117 ill parents (72% ♀); 76 spouses (36% ♀)	1. Breast 32%, gynaecologic 21%, brain 12%, haematological 10%, others 25%; 2. I: 33%, II: 28%, III: 22%, IV: 17%; 3. Mean 8.6 weeks
2. Compas et al. (1996) ¹⁷	32 latency-aged children (47% ♀); 59 adolescents (54% ♀)	1. Breast 28%; gynaecologic 20%; haematological 10%; lung 7%; others 35%; 2. I: 36%, II: 24%, III: 21%, IV: 19%; 3. Mean 9.8 weeks
3. Grant and Compas (1995) ¹⁹	55 adolescents (33♀, 22♂), aged 11–18 years	1. Breast, ovarian, leukaemia, Hodgkin and others; 2. I: 36%; II: 24%; III: 21%, IV: 19%; 3. Mean 8.6 weeks
4. Howes et al. (1994) ²¹	19 ill mothers of 32 children (18♀, 14♂), aged 3–18 years	1. Breast; 2. I–IV; 3. Mean 32.8 mo, range 7–117 mo
5. Huizinga et al. (2003) ²⁴	15 children (10♀, 5♂), aged 7–18 years from 14 families; 14 ill parents (13 mothers, 1 father); 12 spouses (11 fathers, 1 mother)	1. Breast 71%; germ cell tumor 7%; soft tissue sarcoma 7%; ovarian 7%; testicular 7%; 2. N.i.; 3. 2–52 months post-treatment
6. Lewis et al. (1996) ⁷	22 single ill mothers; 25 latency-aged children and adolescents 101 partnered ill mothers; 106 latency-aged children and adolescents	1. Breast; 2. 0–II; 3. Median 18 mo
7. Lichtman et al. (1984) ⁴¹	78 ill mothers; 63 significant others (spouses 73%); 3 physicians	1. Breast; 2. I: 31%; II: 55%; distant metast.: 14%; 3. Mean 25.5 mo; range 1–60 mo
8. Mireault and Compas (1996) ²¹	11 adolescents (6♀, 5♂)	1. Cancer (N.i.); 2. N.i.; 3. T1 at diagnosis
9. Nelson et al. (1994) ¹³	24 adolescents (8♀, 16♂), aged 11–21 years from 16 families	1. Hodgkin 43.6%; Non-Hodgkin 12.6%; breast 43.8%; 2. II: 3; III: 1; IV: 3; Incurable: 2; High risk relapse: 2; ongoing disease: 1; unknown: 4; 3. Range 2–6 years
10. Nelson and While (2002) ²²	34 latency-aged children and 46 adolescents (46♀, 34♂) 80 ill parents (68♀, 12♂) 64 spouses	1. Breast 63%; lymphoma 11%, leukaemia 6%, gynaecological 4%; testicular 4%; 2. N.i.; 3. One year
11. Siegel et al. (2000) ²³	119 children (50% ♀, aged 7–16 years) from 77 two-parent families 77 well parents (57% ♀)	1. Cancer (N.i.); 2. Terminal disease; 3. Mean 2 years
12. Sigal et al. (2003) ³⁴	42 women with metastatic and 45 women with non-metastatic breast cancer with children aged 6–18 years	1. Breast cancer; 2. Metastatic vs. non-metastatic; 3. N.i.
13. Vess et al. (1985) ⁴²	54 patients (30♀, 24♂) and 54 spouses of children under age 20 years living at home	1. Cancer (N.i.); 2. N.i.; 3. N.i.

N.i., no information; 0, I, II, III, IV, stage of disease as described by authors (stage 0, in situ).

Based on the above mentioned quality criteria nine of the 27 quantitative studies and mixed-method studies,^{8,12,14,17–19,23,34,37} were qualified as methodologically stronger studies. Eighteen of the 30 qualitative and mixed-method studies were qualified as trustwor-

thy.^{6,10,11,17–19,23,24,29–31,33,40,43,44,46–48} It appeared that some mixed-method studies have a strong qualitative and a poor quantitative part or vice versa. The references of methodologically stronger (parts of) studies are presented in the text in bold and the other references in italic.

The reviewed studies reported on children of various ages. Although a few studies presented the results without making a distinction between age groups, most studies focused on specific age groups or presented the results for school-aged (about 6–11 years) and adolescent children (about 12–18 years) separately. Therefore, this classification will be used in this review. Four qualitative studies examined the functioning of pre-school children,^{6,30,40,42} but generally did not describe the results for pre-school children separately.

Furthermore, it may be argued that the experience of a stressful life event may have also positive consequences (e.g. deepening of relationships). Most studies have focused on the negative impact of parental cancer, but if positive consequences were reported by studies, these will be described.

The impact of parental cancer on the psychosocial functioning of children

Emotional functioning

Most quantitative studies reported that school-aged children scored within the normal range on emotional problems,^{8,15,18,20,21} while some other studies found increased scores.^{12,14} With regard to adolescents, most studies reported more emotional problems in adolescents when compared to control or norm groups.^{2,8,12,13,14,15,18} Yet, there were also a few studies that found similar emotional problems in adolescents than found in norm groups.^{16,20,21} Stress-response symptoms (avoidance and intrusive thoughts) were also observed in school-aged and adolescent children.¹⁸ Qualitative studies showed that school-aged children reported fear of cancer symptoms, side effects of treatment, the parent dying and of the vulnerability of the well parent. They reported feelings of guilt, because they considered themselves responsible for the occurrence of their parent's cancer, for their parent's anger, withdrawal, or lack of affection. Besides, they were distressed about loss of their usual activities and loss of contact with their peers.²⁵ Adolescent daughters were found to have increased psychosomatic symptoms and mood disturbances. They also reported fear of developing breast cancer themselves, fear of relapse, fear of losing their mother, anger, and guilt, because they wished to continue their own lives.^{26–28,29} Adolescents were afraid of being left alone with their ill parent, because they were worried about making mistakes in the care of this parent.⁴⁸

Social functioning

Quantitative studies did not show any differences in social competence (skills in social contacts and leisure activities) between children of parents with cancer and a norm group.^{14,20,21} Qualitative studies focused mainly on relationships of children with family members and friends. School-aged children reported to have no one to help them cope with the situation.¹⁰ Adolescents reported to have more people (parent, school nurse or counsellor, teacher) to rely on than younger children.²⁶ One study found that adolescents perceived the home environment as supportive,⁴⁸ while another found that adolescent daughters had a need for more support from inside their family.²⁷ School was an important source of support for adolescents⁴⁷ and served as a haven away from care-provision.⁴⁸

Behavioural functioning

Quantitative studies using self-report data from youngsters^{2,10,29} and/or data from parents^{8,9,14,20,21} did not show any differences in the prevalence of behavioural problems (e.g. externalising: delinquency or aggression) between school-aged or adolescent children of cancer patients and norm group children. Qualitative studies reported various results. Increased crying, clinging and difficulty in sleeping were found in pre-school children.³⁰ School-aged children's behavioural reactions included a change in the intensity of talking, trying to distance themselves from cancer, increased checking on how the ill mother was doing, taking over the mothering role, seeking physical closeness or withdrawal,¹¹ having increased conflicts with parents, siblings and peers,²⁵ and paying more than usual attention to the mother's needs and wanting to support her.¹⁰

Cognitive functioning and school performance

Qualitative studies reported that school-aged children were unable to concentrate and complete assignments at school.²⁵ Some adolescents showed a decline in school performance and attendance (truancy, coming late or leaving earlier to pick up siblings),^{13,27,28} while other adolescents functioned better at school.⁴⁸

Physical symptoms

According to one quantitative and two qualitative studies parents reported somatic symptoms, such as sleeping difficulties and headaches, in their pre-school³⁰ and school-aged children.^{6,15} School-aged children themselves also reported sleeping problems.²⁵ Adolescent daughters indicated that they suffered from a variety of symptoms, including headaches, abdominal pain, dizziness, sleeping

problems and loss of appetite.^{27,28} Youngsters who were caring for their ill parent reported fatigue.⁴⁸

Relationships between study variables and child functioning

Child variables

Age. Quantitative studies found more emotional problems in adolescents than in school-aged children.^{2,8,18,26} School-aged children, however, showed more stress-response symptoms than adolescents.¹⁸ Qualitative studies documented that pre-school children were reacting on non-verbal and stressful behaviour of the parent and separation from the mother.⁶ School-aged children were more affected by the visible symptoms of the illness and side effects of treatment, such as vomiting and loss of hair.^{25,31} Complications and emergency hospitalisations were especially disturbing for school-aged children.²⁵ Adolescents were more preoccupied with the well being of their parent¹⁵ and were more inclined to talk openly about their thoughts and feelings about cancer than younger children.¹⁰

Gender. The methodologically stronger quantitative studies found more emotional problems in adolescent daughters of mothers diagnosed with cancer than in daughters of fathers with cancer, or in sons of mothers or fathers diagnosed with cancer.^{8,18,19} Adolescent daughters reported also the highest scores on aggressive behaviour, independent of the ill parent's gender.⁸ Otherwise, the methodologically poorer studies found no gender differences for emotional problems, behavioural problems and social competence,²¹ or found higher anxiety-scores and lower self-esteem in adolescent sons than in adolescent daughters.^{13,22}

Parental variables

Illness-related variables. Quantitative studies found no relationship between child functioning and type and stage of cancer, time since diagnosis,^{8,18} illness severity and treatment modalities.²⁰ Children whose parents suffered from advanced stage disease and a poor prognosis seemed to perceive their parent's illness as more serious and stressful, and avoided thinking about their parent's cancer.^{17,18} These children were reported to have fewer externalising symptoms than children of parents with non-advanced stage illness.³⁴ Qualitative studies revealed a negative impact on the mother-child relationship when the mother had a poor prognosis, extensive surgery, and suffered more side-effects from radiotherapy and chemo-

therapy.^{35,41} The period of diagnosis and treatment, and when the illness situation decreased seemed to be most difficult for school-aged and adolescent children, because of the uncertainty and the diminished availability of their mother.^{6,11,27,33,46}

Five studies paid attention to the impact of gender-specific cancers or hereditary risks on children. One quantitative study found no differences in anxiety/depression and stress-response symptoms between daughters of mothers who had gender-specific cancer (breast or gynaecological cancer) and daughters of mothers who had non-gender-specific cancer.¹⁸ Adolescents who worried about their own chances of developing cancer, however, showed more withdrawal and somatic problems.¹⁶ Qualitative studies reported that school-aged daughters were aware of their vulnerability when their mother and grandmother had breast cancer.²⁵ Adolescent daughters showed increased high-risk behaviours, such as delinquent behaviour and the use of drugs, as a consequence of fear of getting the disease themselves.²⁸ However, another study reported that most adolescent daughters knew that they were at risk for breast cancer, but did not perceive this as a continuous threat.⁶

Parent psychological functioning. Quantitative studies found that better psychological functioning of the ill parent was associated with better psychological functioning of the child,^{15,20-22} a higher self-esteem,²³ and a better mother-child relationship.⁴¹ However, another study found no relationship between the parent's psychological functioning and that of the child.¹⁸ Worse psychological functioning of the ill parent was also related to positive effects: adolescent children of more anxious and distressed mothers were found to be socially more competent.²⁰

Family variables

Parent-child relationship. Results of the qualitative studies concerning the consequences of the parent's illness on the parent-child relationship varied within studies from an improvement in the parent-child relationship, to no change, to increased conflicts.^{6,13,25,41} Adolescents who had a poor relationship with the well parent or with both parents before the diagnosis found it more difficult to adapt to the illness.^{25,26} Contradictory results were found for the effect of the gender of the child. Two studies showed that mothers experienced deterioration in the relationship with their daughters, but an improvement in the relationship with their sons,^{40,41} while in another study parents indicated that they talked more

sensitively with their daughters than with their sons.⁶

Marital functioning. Greater marital satisfaction had a positive impact on the child's psychological functioning, on family functioning, family coping,^{35,36,37,38} quality of the parent-child relationship^{36,37,38} and on the adolescent's self-esteem.³⁵

Family structure. Quantitative studies found that school-aged children of single mothers had lower scores on global self-esteem and social acceptance, and they seemed to have higher scores on behavioural problems⁷ and stress levels⁶ than children of two-parent families. Results obtained on adolescents of single mothers, however, showed that the quality of the parent-child relationship and self-esteem were equal to those in adolescents living in two-parent families.⁷ Adolescents from two-parent families and those with siblings had less involvement in the illness process than adolescents from single-parent families or only children, and their normal daily lives were less disrupted.^{42,48}

Changes in role. Qualitative studies revealed that although parents attempted to continue the daily life of their children as far as possible,^{24,33} the illness blurred the roles in families.^{6,33,44} Adolescents had to do more household chores^{1,13,48} and perceived increased care responsibilities for siblings and the ill parent.^{13,48} Absence of home health care was an additional burden for them.²⁴ Care-provision duties depended on the severity of the illness and the number of available care-providers, and were experienced as hard work, but also as gratifying.⁴⁸ The way the new roles were divided was important: tasks performed voluntarily, instead of being compelled, had significant positive effects in terms of less role strain and role conflicts, which resulted in better family functioning.⁴² Care for the ill parent provided by daughters had a more intimate nature than that provided by sons.⁶ Taking care caused anxiety in adolescent daughters, because they were afraid that this changed role would definitively alter their relationship with their mothers,²⁸ and also in adolescent sons.¹³

Family functioning. Quantitative studies reported that a high number of illness-related demands had a negative effect on family functioning.^{35,36,38} In families that were functioning fairly well, parents and/or children functioned better.^{24,32,35,38} and the parent-child relationship was better.^{35,36,38} Families with adolescents only were more organised than families with school-aged children or children

of both age-groups; they experienced more family cohesion, less family and role conflicts, and less role strain.⁴²

Family communication. Qualitative studies showed that communication about the illness was of particular concern to parents. It was difficult for parents to decide what to tell their children about the illness, when and by whom.^{30,44} It was a stressful task for parents to talk with the children, because they lacked knowledge about the illness themselves and were afraid they could not maintain emotional control in front of the children.³⁰ The type of information children received varied.^{1,22,43,44,45} Pre-school children were given simple information about the illness. Parents avoid to use words like cancer and dying.⁶ School-aged children were generally informed about the situation,⁶ but often appeared to be misinformed or had misconceptions about their parent's illness and treatment, probably due to their limited cognitive development.²⁵ Adolescent children were informed more extensively than younger children.^{6,45} The increased cognitive capacities of adolescents allowed them to understand the implications of cancer, and many of them searched for information about cancer and treatment in addition to that received from their parents.²⁶ In spite of this, another study reported that adolescents had a need for more information and support from family members and persons outside of the family.⁴⁶ Generally, children of all ages were protected from negative test results, such as new lumps,⁶ although adolescents tended to be informed about the possibility of death when the parent became terminally ill.¹ Reasons to withhold information from children were that parents wished to avoid children's questions about cancer and death, and belief that children were too young to understand.^{6,43} Parents tried to protect their children from fear and worries, although they perceived at the same time that they communicated openly with their children about the disease.^{40,43} Exchanging information with their children and talking with each other served as a means of decreasing distress.^{43,44} Whereas one study did not find any relationship between family communication and child functioning,²² other studies demonstrated that poor family communication or non-communication increased the risk of problems in children,^{25, 28} and in the parent-child relationship.¹³

Informant agreement

Parental agreement. Fathers observed similar levels of anxiety/depression or aggression in their

children as compared to mothers.⁸ Ill parents and partners agreed the most about adolescents' externalising symptoms and the least about children's social competence.¹⁴

Intergenerational agreement. Parents and children agreed moderately on children's emotional and behavioural functioning, particularly regarding externalising behaviour.¹⁴ Self-reports of children revealed more emotional and behavioural problems than parents-reports.^{8,9} Problems of the child may escape the parent's attention because children hide their emotions.^{15,21}

Intervention studies

Intervention studies were aimed to help family members to communicate more openly with each other and to increase their coping strategies.⁴⁹⁻⁵⁵ All papers reported positive effects of the interventions, including less anxiety and more open communication.

Discussion

The first aim of this study was to examine the impact of parental cancer on children, in terms of emotional, social and behavioural, cognitive and physical functioning. The majority of quantitative studies were aimed at evaluating the emotional functioning of children who have a parent with cancer. Results for school-aged children were inconsistent, varying from more emotional problems to equal functioning in comparison with their peers. Nearly all studies reported that adolescents had more emotional problems than found in the norm group. Adolescents may have an increased vulnerability because of the conflicting demands of on the one hand the developmental task to separate from the family and the need to direct to relationships outside the family, but on the other hand the confrontation with the practical, psychological and social tasks demanded by the illness.^{2,6,26}

In the domain of social and behavioural functioning, school-aged children and adolescents were not found to differ from control or norm group peers. It might be that children were doing well on these domains. Otherwise, children may try to protect the parent by showing less behavioural problems. None of the quantitative studies focused on cognitive functioning, and only one on physical

functioning, describing sleeplessness and headaches.

The qualitative studies gave a different view on the four domains of school-aged children's and adolescents' functioning. In the emotional domain, fear, mood disturbances, feelings of distress and guilt were described. Besides, several qualitative studies found a variety of behavioural, cognitive and/or physical problems in children.

The second aim of this study was to examine relationships between child, parental and familial variables and child functioning. It may be assumed that children respond to parental cancer in various ways. Firstly, the reactions of children may be affected by their developmental level. Although studies reporting on children between the 0 and 20 years of age were included, results on the functioning of pre-school-children were limited or were not described separately from other age groups. This means that no general pronouncement can be made about the impact of parental cancer on pre-school children. Comparison with other age groups showed that adolescents were reported to have more emotional problems than school-aged children. This may be due to their cognitive capabilities, as a result of which adolescents are more aware of the consequences of the illness.¹⁸ Particularly, adolescent daughters of mothers with cancer seemed vulnerable: they had more emotional problems than adolescent sons in general and adolescent daughters of fathers with cancer. Probably, adolescent daughters are more vulnerable due to the identification with their mothers and increased role responsibilities.^{18,56}

Emotional problems may be affected by the child's perceptions of the seriousness and stressfulness of the illness and a poor prognosis rather than other objective disease characteristics (such as type, stage, and time since diagnosis).

The majority of the studies reviewed found a positive relationship between the psychological functioning of the parent and the child, which is in line with the results of a meta-analysis on maternal depression and child's functioning.⁵⁷ On family level, open communication between the family members and greater marital satisfaction between the parents had a positive effect on child functioning. Varying results were found regarding the effects of parent-child relationships, changes in role patterns within the family, family structure and family functioning on children's functioning.

The non-uniformity in results may be due to the heterogeneity in research questions, methodology, illness-related characteristics and different informant perspectives.

The majority of studies evaluated the psychosocial functioning of the child, but in some studies family functioning, family communication, school support or care-provision played a central role.

Quantitative studies used a variety of questionnaires to measure psychosocial functioning in children (e.g. internalising problems versus anxiety alone). However, it may be questioned whether the questionnaires used were sensitive enough to measure the specific problems children encounter when a parent has cancer.

A number of studies had fewer than 50 respondents, which may have lead to type II errors. Moreover, in the majority of studies, cross-sectional data were described, which means that no conclusions could be drawn about causal relationships. Furthermore, over half of the studies did not give any information about the response rate, or the response rate was low. This raises the question as to whether the populations can be considered representative of all families in which a parent has cancer.

In a number of qualitative studies the methods of analysis were described only briefly. All qualitative studies used (semi)structured interviews, but it remained unclear what had exactly been performed, which limits the credibility, dependability and confirmability of those studies.

Many of the studies (quantitative and qualitative) focused specifically on patients with one certain type (e.g. breast cancer) or stage of cancer (stage I/II or terminal disease), whereas other studies included various diagnoses and stages of disease. In addition, the time since diagnosis varied widely, from a few days to nine years. A number of studies included children of considerably different ages, but did not make any distinctions regarding age or developmental level when presenting the results. This may have limited the generalizability and transferability of the results.

Different informants (parent/child) did not always have the same perceptions of child functioning. Parents as a whole tended to show a higher level of agreement on behavioural problems than on emotional problems. This may not be surprising because behavioural problems are easier to detect.

Finally, the third aim of this study was to examine whether evidence-based interventions are described for families in this situation. Though the reviewed intervention studies reported all positive outcomes, these results were based on impressions of the facilitators, verbal feedback from participants and on self-constructed, non-validated questionnaires. The effectiveness of these interventions has not been examined in randomised

controlled trials and may therefore not be considered as evidence-based.

Future directions

In view of the diversity of results, as shown in this extensive review, it is extremely important to perform higher quality research into the psychosocial functioning of children who have a parent with cancer. Quantitative studies with large numbers of respondents have greater power. In addition, larger samples offer the opportunity to compare subgroups, for example differences between children whose parent has a good prognosis and children whose parent has a poor prognosis. Longitudinal studies are needed to gain more insight into the causal relationships between child functioning and the above-mentioned variables and into the long-term consequences.

The majority of the studies were performed among families of breast cancer patients. Although breast cancer is the most common disease in parents with children, more information is needed to gain insight into the functioning of children of fathers diagnosed with cancer. Further research is also needed about the functioning of pre-school children in this situation.

It is important to develop and validate an instrument that specifically measures the psychosocial functioning of children whose parents were diagnosed with cancer.

With respect to the differences in outcomes between quantitative and qualitative studies, it seems advisable to combine these study methods (method triangulation). For instance, the results of a large quantitative study on child functioning can gain in strength when combined with the results of a qualitative study with in-depth interviews with those children (and parents) reporting extremely high or low levels of functioning.

There is no 'golden standard' regarding who is the best informant of child functioning. It is therefore worthwhile to triangulate perspectives, not only from the parents and children, but also from a significant other (such as school-teachers).

Some children may be more vulnerable than others. It is therefore important to identify factors that may act as facilitators or as barriers. Consequently, studies are needed to establish the role of child characteristics (such as gender, developmental phase, personality), parental characteris-

tics (such as psychological functioning, marital satisfaction, up-bringing style), family characteristics (such as parent-child communication, role changes within the family) and illness and treatment related variables. A theoretical model can serve as a guide to gain insight into the complexity of child functioning within families confronted with cancer. With more structured and well-grounded knowledge appropriate interventions may be developed for children and families at risk.

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